



Summary

National Strategy for Palliative Care 2013-2015

Results 2010-2012 and
need for action 2013-2015



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Major Objective of the National Strategy for Palliative Care

The Confederation and cantons will collaborate with the most important actors in the field of public health and in other areas to integrate palliative care. This will allow all critically ill and dying people in Switzerland to receive palliative care that is adapted to their needs in order to improve their quality of life.

1 Initial Situation

On 25 October 2012 the «Dialogue on national health policy», the common platform of the Confederation and the cantons, adopted the «National Strategy for Palliative Care 2013–2015». The «National Strategy for Palliative Care 2010–2012» was thus extended for another three years.

Throughout the course of the initial strategy, many measures were implemented in the past three years in the six sub-projects “Care”, “Financing”, “Awareness”, “Training”, “Research” and “Interdisciplinary sub-project”. However, the main objective cited above was not completely achieved. The broad implementation of the established principles still needs to be completed in many areas. The period of three years determined for implementing the measures defined in the strategy was too short based on the available personnel and financial resources.

This summary of the “National Strategy for Palliative Care 2013-2015” presents the overall results in the six sub-projects of the “National Strategy for Palliative Care 2010-2012”. The action needs, the objectives and measures for progressing the 2013-2015 strategy in the various areas will also be laid out.

1.1 Palliative Care

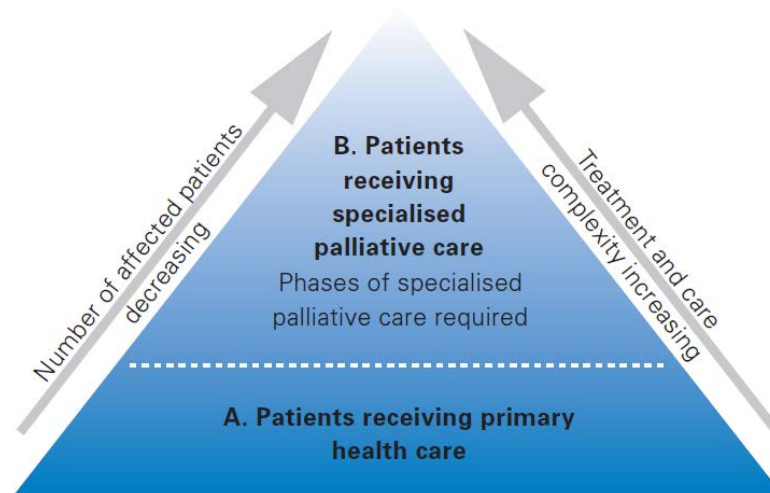
According to the “National Guidelines for Palliative Care”, palliative care comprises “the care and the treatment of persons with incurable, life-threatening and/or chronically progressive illnesses”. It is proactively taken into account, but its focus is on the time when the cure of the disease is no longer considered possible and no longer represents the primary objective. Patients are guaranteed an optimal quality of life depending on their situation until they pass away, and closely related persons receive adequate support. Palliative care prevents suffering and complications. It includes medical treatments, nursing interventions as well as psychological, social and spiritual support.¹

The 4th guideline “Target Groups” stipulates that palliative care focuses on the needs, symptoms and problems of patients as well as their relatives and friends. Because of their different needs, a distinction is made between patients receiving primary palliative care (patient group A) and patients receiving specialised palliative care (patient group B) (see Fig. 1). Primary care in this case is understood as long-term care, acute hospital care as well as out-patient care provided by GPs or primary care teams as well as other health professions.²

¹ Federal Office of Public Health (FOPH) and Swiss Conference of the Cantonal Ministers of Public Health (CMH) (2010) National Guidelines for Palliative Care

² Practising physicians with a postgraduate title General Medicine, Internal Medicine and General Internal Medicine, Paediatric and Adolescent Medicine as well as practising physicians with General Medicine as the sole postgraduate title are designated as the primary care physicians. Additional health professions include qualified nurses, pharmacists, midwives, qualified physiotherapists and occupational therapists, dieticians as well as assistant professions such as medical assistants or health specialists. cf. Swiss Conference of the Cantonal Ministers of Public Health (CMH) and Federal Office of Public Health (FOPH) (2012): New models for care in medical primary care. Report of the working group “New models for care in medical primary care” by CMH and FOPH p. 5

Fig. 1: Target groups for palliative care



Source: FOPH and CMH (2010): National Guidelines for Palliative Care

The transition between these two groups is fluid. This means that patients may belong to both groups over the course of their illness. Because a sick person may temporarily be doing better, the phases of instability and complexity of group B alternate with phases of group A.

1.2 Palliative Care in Switzerland:

The need for palliative care will increase significantly in the coming years. The present age distribution of the Swiss population in the long term will lead to an ageing of society:³ The 'average' scenario of the Federal Statistical Office (FSO) predicts that the percentage of those aged 65 and above in the population will increase from 17 per cent in 2010 to 28 per cent in 2060.⁴ The demographic development involves an increase in the number of old people who will require nursing care. The health care system must prepare itself for the fact that medical treatment and care during the last phase of a person's life will become more complex.

At the same time, due to the changed age distribution, the annual number of deaths will also increase: at present in Switzerland there are about 60 000 deaths each year for all ages. Current scenarios for the demographic development estimate a significant increase in deaths for the coming years. Thus, the FSO predicts a one third increase in the number of deaths within the next 20 years, i.e. rising from 60 000 to 80 000 people per year.⁵

The number of palliative care patients will most likely also increase along with the predicted increase of annual deaths. On the basis of today's figure of 40 000 people per year who require palliative care (estimate from international studies), this number should rise to the order of 53 000 people over the next 20 years. This increase will have a major impact in the area of primary palliative care:

³ Swiss Federal Statistical Office (SFSO): Future population development – data, indicators – Switzerland, scenarios. <http://www.bfs.admin.ch/bfs/portal/de/index/themen/01/03/blank/key/intro.html> (accessed April 2012)

⁴ The SFSO has recently issued three base scenarios for the future development of the population in Switzerland: the "low", the "average" and the "high" scenario. Here, the "average" scenario is taken as the reference scenario. This scenario is based on the continuation of the developments of the last years, SFSO (2010): Scenarios for the Development of the Population in Switzerland 2010–2060. Neuchatel, p. 5

⁵ Swiss Federal Statistical Office (SFSO): Future population development – data, indicators – Switzerland, scenarios. <http://www.bfs.admin.ch/bfs/portal/de/index/themen/01/03/blank/key/intro.html> (accessed April 2012)

	2012	2032
Total deaths in Switzerland	60'000	80'000
Total number of palliative care patients (estimate: two thirds)	40'000	53'000
Of which patients needing primary palliative care (estimate: 80%)	32'000	42'000
patients needing specialised palliative care (estimate: 20%)	8'000	11'000

Table 1: Number of palliative patients in Switzerland in 2012 and 2032 (estimation)

In view of the demands for a strengthened integrated medical care of the population and for reduced healthcare costs, the promotion of palliative care corresponds with the direction of the strategic health policy of the Confederation and cantons.

2 Results of the “National Strategy for Palliative Care 2010-2012”

The implementation of the measures began in January 2010 in the six sub-projects «care», «financing», «awareness», «education and training», «research» and «interdisciplinary sub-project». The overall direction of the strategy rests with the Federal Office of Public Health FOPH. The joint management of the sub-projects included representatives from the Swiss Conference of the Cantonal Ministers of Public Health CMH (care and financing), the Federal Office for Professional Education and Technology OPET (education and training), the Federal Statistical Office FSO (research) as well as the Swiss Association for Palliative Medicine, Care and Support «palliative ch» (care, awareness).

Most of the measures of the strategy phase 2010 to 2012 involved the preparation of broadly agreed basic principles in the field of palliative care – both in regard to the definition, as well as relating to the areas of care structures, quality, training, awareness raising, financing or research.

2.1 Interdisciplinary sub-project

- **National Guidelines for Palliative Care** The “National Guidelines for Palliative Care” were developed under the direction of the FOPH. They define palliative care and formulate the fundamental values and principles, describe the target groups, the settings for treatment and support as well as the service providers of palliative care. A broad circle of stakeholders from the whole of Switzerland participated in the preparation.

2.2 Sub-project Care

- **Care structures for specialised palliative care** The FOPH, CMH and “palliative ch” collaborated to draw up the “Care structures for specialised palliative care”. The document offers an overview of the required services in primary palliative care and in the specialised palliative care for the cantonal health and social departments and the local, regional and cantonal service providers.
- **Definition of Quality Criteria** Under the auspices of the Association “palliative ch”, three lists of quality criteria were prepared for specialised palliative care clinics and units (List A), for in-patient and mobile out-patient palliative services (List B) and for in-patient treatment in institutions for long-term care.
- **Verification of the quality of palliative care services** Under the auspices of “palliative ch”, the Swiss Association for Quality in Palliative Care “qualitépalliative” was founded. It awards the label for Quality in Palliative Care.
- **Care Planning in the cantons** The cantons were supported in their care planning with an information event for the cantonal public health departments, and a survey on the state of palliative care services.

- **Indication criteria for specialised palliative care** A working group under the direction of the CMH prepared the “indication criteria for specialised palliative care”. They serve as a guideline for decision making when specialists need to be consulted or when the patient needs to be transferred into a specialised palliative care unit.

2.3 Sub-project Financing

- **Report “Provisions of palliative care in primary care and in the specialised field of out-patient and in-patient long-term care and their financing”** The report, prepared by the CMH and the FOPH, describes in detail the situation in regard to financing and identifies the major problems.
- **Amending the Health Care Benefits Ordinance** The Federal Department of Home Affairs (FDHA) adapted Article 7 paragraph 2 letter *a* of the Health Care Benefits Ordinance KLV as of 1 January 2012. The paragraph is now entitled “Measures for clarifying, advising *and coordination*”.
- **Tarification of palliative care provisions in palliative units and clinics** A working group under the auspices of “palliative ch” has the remit to create a performance-related, tariff structure that is uniformly applicable throughout Switzerland.

2.4 Sub-project Awareness

- **National Information Platform Palliative Care** The “National Information Platform Palliative Care” www.palliative.ch came on line on 30 August 2010 for patients, interested parties and professionals.
- **Key Messages on Palliative Care** In the scope of the communication concept on palliative care, key messages were prepared. They serve as guidelines such that palliative care can be presented in a uniform manner. These key messages were assessed in a preliminary test for their comprehensibility and acceptance by the public.
- **Brochure “Terminally ill – what to do now?”** With the brochure “Terminally ill – what to do now?”, prepared by the FOPH, CMH and palliative ch, the cantons and regions now have a ready-for-use information sheet available.

2.5 Sub-project Education and Training

- **National Concept «Palliative Care: Education and Training»** The FOPH and the Federal Office for Professional Education and Technology OPET, together with representatives of the organisations concerned and significant stakeholders, prepared a national concept on education and training in palliative care.
- **Integrating the knowledge and skills needed in palliative care in the learning objectives catalogue of the university medical studies** It was agreed with the Swiss Medical Inter-Faculty Commission (SMIFC) to establish a broader inclusion of palliative care learning objectives in the Swiss catalogue of learning objectives (SCLO). The Undergraduate Education Palliative Care working group, composed *inter alia* of representatives of the medical faculties of Switzerland, determined in an analysis of the current situation the need for action in various medical faculties and developed corresponding recommendations and solutions.
- **Establishing palliative care as an integral part in postgraduate & further education** Discussions are ongoing with the Association for Palliative Care and the Swiss Institute for Postgraduate & Further Education in Medicine (SGCI) and various Associations in order to clarify how and to what extent palliative medicine should be firmly established in postgraduate training courses and the corresponding postgraduate programmes.
- **Forum “Education, Training and Working in Palliative Care”** The forum “Education, Training and Working in Palliative Care” was created for discussing the implementation of the national training concept in the various study programmes and at the various course levels.

- **Preliminary analysis of postgraduate training in long-term care institutions** Curaviva received the mandate to prepare a report (preliminary analysis) on the promotion of in-house training in palliative care for employees without a specific training and/or with training as an assistant in residential or nursing homes, institutions for the handicapped and for community care employees (without formal training) in the out-patient field. This involved the collaboration with important stakeholders.
- **Concept «Training and Support for Voluntary Work in Palliative Care»** Under a mandate from the FOPH, a «National Concept Training and Support for Voluntary Work in Palliative Care» was developed by Caritas Switzerland and the Swiss Red Cross SRC. This defined the roles of volunteers in palliative care and proposed measures for an improved involvement.

2.6 Sub-project Research

- **National Research Programme “End of Life” (NFP 67)** Parallel to the development of the National Strategy for Palliative Care, a proposal for a national research programme NFP was written under the auspices of the FOPH. The Federal Council commissioned the Swiss National Science Foundation SNF in early 2010 to carry out the NFP 67 “End of Life”.⁶
- **Chair and Programme for the Promotion of Palliative Care of the SAMS** At the request of the FOPH the Swiss Academy of Medical Science SAMS examined its possibilities for promoting research in palliative care. In autumn 2012 it decided to create a long-term “endowed chair for palliative medicine” at a faculty of medicine and to launch a promotional research programme in palliative care.
- **Research Platform Palliative Care** The “platform for research in palliative care and end of life” (Iprpc) has already been in place for some time in French-speaking and Italian-speaking Switzerland. A similar platform will be created in German-speaking Switzerland under the auspices of the FOPH and palliative ch.
- **Statistical Data Situation in the field of Palliative Care** In order to obtain an overview of the current data situation the FSO has examined the existing national statistics in regard to variables important in regard to palliative care.

3 Need for Action and Measures 2013-2015

It was shown that important synergies and dependencies exist between the six sub-projects of the first strategy phase. In order to take the indispensable interconnection between the topics more into account and to pool resources, the sub-projects «care» and «financing» as well as «education and training» and «research» were combined. Up to now the topic «volunteer work» was only considered under the sub-project “training”. As this perspective is too narrow, the formal volunteer work will be considered as a independent sub-project in the continuing strategy.

The action plan for progressing the strategy in the years 2013 to 2015 is based on the work of the past three years, the results of the self-evaluation, the feedback and discussions with numerous involved stakeholders as well as from an analysis of the current literature. Furthermore, a «Strategy Forum Palliative Care» was held on 30 May 2012 attended by some 60 representatives of the cantons and various organisations. Suggestions and proposals were put forward in five groups and have been taken into account in the action plan shown below.

⁶ cf. www.nfp67.ch

3.1 Sub-project «Care and Financing»

Need for Action

In the first strategy phase the focus in the area “care and financing” was on specialised palliative care. In the second strategy phase, attention will be directed to primary palliative care. More than 80 per cent of palliative patients can be treated and cared for in the context of primary palliative care. About 20 per cent of palliative patients require specialised palliative care services.

Defining primary palliative care renders the services and provisions of palliative care more comprehensible and consequently also more visible. These are the main prerequisites for seriously ill and terminally ill persons to obtain access to palliative care in Switzerland. In order to promote the implementation of palliative care in the cantons and regions it makes sense to offer a platform for exchange and reciprocal links.

Objectives and planned measures

1. Sub-project «Care and Financing»	
Overall objective of the sub-project	
Sufficient offers of palliative care are available throughout Switzerland. Access to the provision of palliative care is ensured for seriously ill and dying persons, independently of diagnoses, age or socio-economic status.	
1. Subordinate objective:	
The offers and provisions of palliative care in primary care are defined and indication criteria are specified.	
1.1.1	Highlighting the offers and provisions of palliative care in primary care: Definition and indication criteria
1.1.2	Recording the costs for palliative care in the long-term clinical setting and in outpatient care and treatment
2. Subordinate objective:	
Specialised palliative care provisions in inpatient institutions (hospital) and in paediatrics are available when needed.	
1.2.1	Development of a performance-related, uniform tariff structure throughout Switzerland for specialised palliative care in hospitals with palliative care missions (palliative care clinics/institutions)
1.2.2	Survey of the need for palliative care in paediatrics
3. Subordinate objective:	
Regional, cantonal and intercantonal synergies relating to strategies and offers in the field of palliative care as well as financing models are promoted by information exchanges between the cantons and the provision of implementation variants and best practice models.	
1.3.1	Support of the cantons in the implementation of required palliative care structures by the preparation of an exchange and information platform.
1.3.2	Promotion of eHealth applications in palliative care (benefits study)

3.2 Sub-project «Education, Training and Research»

Need for Action

In the last two years the “National Strategy Palliative Care” has created solid bases for strengthening palliative care in the areas of training and research. The work already begun should therefore be continued. In this regard the basis forms a consensus among all relevant stakeholders on the training objectives in palliative care. Moreover, specific measures for the various training levels have to be implemented in the sub-project “Training”.

The promotion of research and the improvement of the basic data must also continue to be pursued in the coming years. Statistical data on the end of life should be increasingly analysed. The data form an important foundation for health care planning in the cantons and regions. Closing the existing gaps in training, teaching and research in palliative care will improve the quality of health care at the end of life for everyone.

Objectives and planned measures

2. Sub-project «Education, Training and Research»	
Overall objective of the sub-project Specialists and teachers who are active in palliative care are provided with the required appropriate level of expertise. Teaching and research in palliative care in Switzerland are significantly consolidated and contribute to the quality of health care at the end of life.	
1. Subordinate objective: The joint education concept “Palliative Care and Training” forms the basis for a coordinated implementation.	
2.1.1	Annual forum “Training and Working in the world of Palliative Care”
2. Subordinate objective: Palliative care is an integral component of the training, further education and continuous education of the university and the non-university health and social professions as well as for other relevant occupational groups.	
2.2.1	Incorporating palliative medicine in medical training
2.2.2	Incorporating palliative medicine in medical postgraduate training
2.2.3	Incorporating palliative care in non-university health and social professions as well as for other relevant occupational groups
2.2.4	Clarification of further action relating to the promotion of in-house training of non-specialised employees
2.2.5	Incorporating palliative care in non-medical university courses
3. Subordinate objective: Measures for the promotion of research in palliative care are continued.	
2.3.1	Promoting networking and coordination in palliative care research
2.3.2	Providing basic data relating to palliative care

3.3 Sub-project «Awareness»

Need for Action

The build-up of palliative care offers will only be successful when people know what palliative care is. In spite of various publicity campaigns, still too little is known about palliative care and its offers, principally in German-speaking Switzerland. It must be said that three years are a very short timeframe in order to make the population aware of a topic that was previously almost unknown. An aggravating factor is that dying and death are also still taboo subjects in Switzerland.

Surveys show that in society today, primarily suicide help organisations are perceived as a possibility for ensuring self-determination at the end of life. Other possibilities that can likewise contribute to strengthen self-determination at the end of life – such as palliative care, end of life arrangements, recognising and treating depression – are not well known in the population.⁷ However, knowledge of these offers is a prerequisite in order to be able to come to a decision on self-determination. Consequently, increased efforts are required in this area. Action is needed principally along the two axes “informing the population” and “informing specialists”.

Objectives and planned measures

3. Sub-project «Awareness»	
Overall objective of the sub-project The population and the specialist professions in Switzerland know about the benefits of palliative care and are aware of their availability.	
1. Subordinate objective: Specialists are made aware of palliative care through suitable channels.	
3.1.1	Informational flyers for specialists
2. Subordinate objective: The information on palliative care for the population is developed for specific target groups.	
3.2.1	Informational flyers on palliative care for the population
3.2.2	Updating the brochure “Terminally ill – what to do now”
3.2.3	Identifying the needs of migrants at the end of life
3. Subordinate objective: The population is made aware of palliative care over suitable channels.	
3.3.1	Constructing a regional communication network
3.3.2	Informing the population

⁷ Federal Council (2011): Palliative Care, Suicide prevention and organised suicide assistance. Report of the Federal Council, p. 35

3.4 Sub-project «Volunteering»

Need for Action

Volunteer work in palliative care in Switzerland is a formal, institutionalised volunteer service that is organised as an independent group or integrated into an inpatient institution or attached to such an institution. Volunteer work in Switzerland today is financed by private and public organisations. Together with the salaried professional staff, volunteers play an important role in palliative care. However, there is a need for action in the areas of health care planning and organisational structures as well as in information on the formal volunteer work in palliative care. This is shown by a needs-assessment commissioned by the FOPH as well as by additional studies.

Objectives and planned measures

4. Sub-project «Volunteering»	
Overall objective of the sub-project The offers and services of the formal volunteer work in palliative care are known throughout the country and are used proactively by cantonal and communal authorities and health and social service organisations as well as by professionals for the care and support of seriously ill and dying patients and their attachment figures.	
1. Subordinate objective: Information is drawn up on the requirements relating to the management and coordination in the formal volunteer work in palliative care.	
4.1.1	Guidelines for the promotion of formal volunteer work in palliative care
2. Subordinate objective: Existing channels are used to promote formal volunteer work in palliative care.	
4.2.1	Existing information platforms are used to promote formal volunteer work
3. Subordinate objective: Information on services and offers of formal volunteer work in palliative care are communicated to the population.	
4.3.1	Dissemination of information for volunteers and the population

3.5 Interdisciplinary project

The interdisciplinary strategy pursues the objective of ensuring that after 2015 the promotion of Palliative Care is sustained in the long-term over and above the support in the context of the “National Strategy Palliative Care” of the FOPH and CMH.

Action Plan

5. Measures for project management	
5.1	Ensuring the long-term sustainability of Palliative Care after 2015
5.2	Supporting a National Palliative Care Day
5.3	Evaluating the National Strategy Palliative Care 2010-2015
5.4	Organising a final meeting in 2015

Further information and all documents are available in pdf form here:

www.bag.admin.ch/palliativecare

www.gdk-cds.ch

www.palliative.ch

The following brochures can be ordered free of charge from the BBL, Bundespublikationen (www.bundespublikationen.admin.ch):

- **National Strategy for Palliative Care 2013-2015** (Order No. 316.720, from November 2012)
- **National Guidelines for Palliative Care** (Order No. 316.716)
- **Indikationskriterien für spezialisierte Palliative Care** (Order No. (316.717)
- **Nationales Bildungskonzept «Palliative Care und Bildung»** (Order No. 316.718)
- **Versorgungsstrukturen für spezialisierte Palliative Care** (Order No. 316.719)